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Practice case study

'This workshop was bright and beautiful': insights into the process of co-production of images for decision aids with marginalised groups

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Peer review

This article has been peer-reviewed through the journal's standard double-anonymous peer-review process, where both the reviewers and authors are anonymised during review.

Abstract

This co-production project worked with groups often marginalised in research, in order to improve the accessibility and inclusivity of two online patient decision aids through the use of images. We share reflections on contributors' experiences, and we make recommendations for other teams using co-production processes. The research team and public contributor panel chair invited people from a South Asian, Caribbean or African background, people aged under 30 or over 65 years, LGBTQI+ people, those living with access needs or disability, and those on a low income or without a job. Contributors reviewed the decision aids in advance, then attended two small-group workshops co-facilitated by an artist to co-create bespoke images. Contributors were reimbursed £50 for each workshop. We held workshops with 18 public contributors from marginalised groups. Five contributors wrote about their reflections on recruitment for the co-production activities, preparation for co-production, contributing to co-production, and next steps, identifying key learning for improving co-production processes. Sharing information before a co-production event is very important for empowering contributors and equalising power. Careful consideration about the potential impact of exposure to the project materials is important, and flexibility in how to contribute makes projects more inclusive.

Keywords co-production; decision aid; marginalised; power; workshops; images

Key messages

- People considering whether to take part in co-production may be discouraged by uncertainties around knowledge requirements, language barriers and group dynamics. Addressing these concerns upfront by being transparent about things such as who contributors will be working with, and sharing information about the activities beforehand, can boost confidence to get involved.
- When an open and friendly setting was created, the public contributors felt more comfortable in giving their views and honest opinions, and they also noted how personally impactful the process of co-production could be. People should be enabled to take part in the way they feel most comfortable (for example, one to one, in small groups, via online chat function), and they should be able to openly discuss aspects such as the potential emotional impact of the co-production work, and personal preferences, for example, having cameras on or off.
- An important incentive for people to become involved in co-production is knowing that their voices matter. Showing the impact of co-production in the real world is powerful, and plans should be in place for continuing to show that impact as a project develops.

Background

Co-production, in which public contributors and researchers work jointly and equally together, taking shared responsibility for decision making on a project, is a valued way of working (Smith et al., 2023). While key principles exist to support productive, equitable and mutually beneficial co-production (Co-production Collective, 2022; NIHR, 2021), it is important to reflect on the co-production process and to understand what it is like for public contributors, and what can be done to make it as inclusive and positive an experience as possible.

This project used co-production to create images to improve engagement and understanding of two online decision aids for people with a genetic predisposition to cancer (Kohut et al., 2024a, b; Morton et al., 2022). The decision aids are hosted on a website called Lynch Choices™, funded by Cancer Research UK (https://canchoose.org.uk/). The decision aids were developed using the International Patient Decision Aid guidelines (Stacey and Volk, 2021), and they focus on supporting people to consider whether to take daily aspirin to reduce the risk of bowel cancer, and whether to have risk-reducing surgery for gynaecological cancers. The decision aids are designed to be used in collaboration with support from a health-care professional.

The person-based approach was followed for developing an in-depth understanding of the beliefs and psychosocial context of the target population during intervention planning and development (Yardley et al., 2015), and a panel of 10 public contributors worked closely with researchers to create the content for the decision aids (Morton et al., 2022). However, the public contributors perceived that the panel lacked diversity, and they agreed on the need to include more perspectives in the co-production of the decision aids, particularly to ensure accessibility.

Best practice guidelines for decision aids recommend that they 'provide ways to help patients understand information other than reading' (IPDAS, 2005: 2). Pictures can improve attention and recall of health information (Delp and Jones, 1996), but they need to be closely linked to text (Houts et al., 2006). In terms of decision aids, research has shown that the use of images is not just a supplementary feature but can be crucial in improving comprehension, particularly for individuals with low health literacy (Durand et al., 2014, 2021; Schubbe et al., 2020). Images help simplify complex medical information, making it easier for patients to understand their options and make informed decisions (Sorensen von Essen et al., 2022). Furthermore, images provide a universal visual language that can resonate across diverse cultural and linguistic backgrounds, which is particularly relevant for marginalised groups. In addition to these benefits, visual aids are especially important for neurodivergent individuals, such as those who are autistic or who have attention deficit hyperactivity disorder, and may process information in a more visual or structured way. Neurodivergent individuals often benefit from clear, structured visual inputs to better comprehend complex concepts (Le Cunff et al., 2024). By including well-designed images in patient decision aids, we can make the information more accessible, and help ensure that information is not misinterpreted, facilitating people to actively engage in decision-making processes. However, it is important that these pictures are perceived as engaging and personally relevant to the target population within their local context (Durand et al., 2016, 2023).

This project aimed to improve inclusivity and to help ensure that the decision aids would be accessible and engaging for as many people as possible. We brought together 18 public contributors who identified with marginalised groups, and an artist specialising in health interventions, to co-produce visual illustrations and to improve the accessibility of the decision aids. Public contributors were reimbursed £50 for each workshop.

We aimed to ensure that people from marginalised groups had the opportunity and confidence to share their ideas about creating images. This article was co-written with five public contributors from marginalised groups who were involved in the project (SK, JL, CB, EP and ST). It shares their reflections and the lead researcher's (KM) reflections on experiences of this co-production project, and it makes recommendations for other teams using co-production processes with marginalised groups.

Process of writing the article

The contributors and the researcher (KM) met regularly throughout the co-production of this article. The contributors used Padlet to write about their experiences of being involved. Padlet is free-to-use software which allows users to post anonymously on an online 'wall' so that everyone can see each other's contributions. It simulates the use of sticky notes to share individual ideas on a shared noticeboard. The idea of using Padlet was suggested by one of the contributors (CB) as an accessible way of writing the article collaboratively and seeing each other's contributions, without needing to install software, and everyone agreed it would work well. Contributions could be anonymous, but all five contributors chose to initial their work.

We agreed to set up four separate Padlets to reflect on the different stages of the project, and to consider what worked well and less well at each stage. These four stages were: (1) recruitment to the workshops; (2) preparation for the workshops; (3) contributing to the workshops; and (4) evaluation of the workshops and next steps. The researcher posted a few questions in each Padlet to help explore what the process had been like, but contributors could share reflections on any aspect of the process.

The next section reports our approach for recruiting, preparing, contributing and evaluating the workshops, followed by the reflections of the contributors. The reflections were collated from the ideas shared on the Padlets through a consensus-based reflective process, facilitated by regular discussions. Excerpts of contributors' posts on each Padlet are included as figures, and a link to each of the Padlets is also provided.

Approach and reflections

Recruitment to the workshops

Recruitment approach

The research team and public contributor panel chair (LT) identified groups often marginalised in research, including people from ethnic minority groups, people aged under 30 or over 65 years, LGBTQI+ people, people on a low income or without a job, and people living with access needs or a disability. We worked with our artist (LB) to design a poster specifically inviting involvement from people who identify with these groups (see Figure 1).

The researchers and the public contributor chair (KM, LT, BC, KK) identified organisations and charities that were more likely to include people from our target groups, including Shine cancer support for younger people with cancer, Live Through This for LGBTQI+ people with cancer, and a cancer information and awareness day in partnership with The Silk Route, a multifaith charity. We also sent the poster to patient and public involvement networks and Macmillan Cancer Support networks, relying on the targeted recruitment on the poster to help ensure that we heard from people who identified with the marginalised groups.

These varied recruitment approaches meant that some contributors had personal experience of cancer, while others did not. Everyone had an interest in making information about cancer more accessible. Ethical approval was gained for the project from the University of Southampton Ethics Committee (Submission ID: 78981).

Reflections of public contributors about recruitment

Figure 2 shows an excerpt from the Padlet where public contributors shared their reflections about the recruitment process for the project.

People have different reasons for getting involved as public contributors in research, but a common thread was that the work needs to feel important and meaningful. The explicit interest in promoting equality and diversity was apparent from the recruitment poster, and this was appreciated as important and made some people more keen to be involved. As one contributor wrote, 'It was really inclusive to see the list of underserved groups we wanted to work with on the poster and made me want to help.'

People were happy to mention which marginalised groups they identified with when getting in touch about the project, although some would have preferred a tick-box form instead of sending an email, as that would have felt easier and less personal. This suggests that offering a form as an option for expressing interest would help more people feel comfortable to get in touch. It is important that the team do everything they can during the recruitment process to make it a warm, welcoming process, and to help people feel confident to get in touch, especially as it is common for people to wonder if they have the skills needed to get involved.

Workshop set-up

Workshop set-up approach

Workshops were held online using Zoom to ensure that no geographical restrictions were put in place. Some in-person workshops had also been budgeted for in case contributors preferred to meet face to face, but in the end all public contributors chose to meet online or by phone.

Workshop dates were organised based on people's availability and preference for whether to view the decision aid about taking daily aspirin to lower the chance of developing bowel cancer, or the decision aid about having a hysterectomy to lower the chance of developing gynaecological cancers (both designed for people who have a genetic predisposition to these cancers).

Figure 1. Recruitment poster

Making Information About Cancer Accessible for Everyone

Are you interested in making information about cancer appropriate and helpful for everyone who might need it?

Do you identify with any of these groups?

- South Asian community
- African or Caribbean community
- Aged under 30 or over 65
- Identify as LGBTQ+
- On a low income or without a job
- Have access needs or living with a disability

I am a health researcher at Southampton University, working with an artist who creates images to help people understand their health.

We invite you to join a small group online or in person.

We will show you some information for people who have inherited a higher chance of getting cancer. **You do not need to have this to take part.**

We will talk about how we can make the information easier to understand, especially using images created by the artist.

We will hold 3 groups from January to June 2023 at times to suit you. You would be paid £50 each time. This covers the 1 hour workshop and a bit of reading we would ask you to do in advance.

If you don't want to take part in a group but still want to tell us your views, please let us know. We still want to hear from you another way.

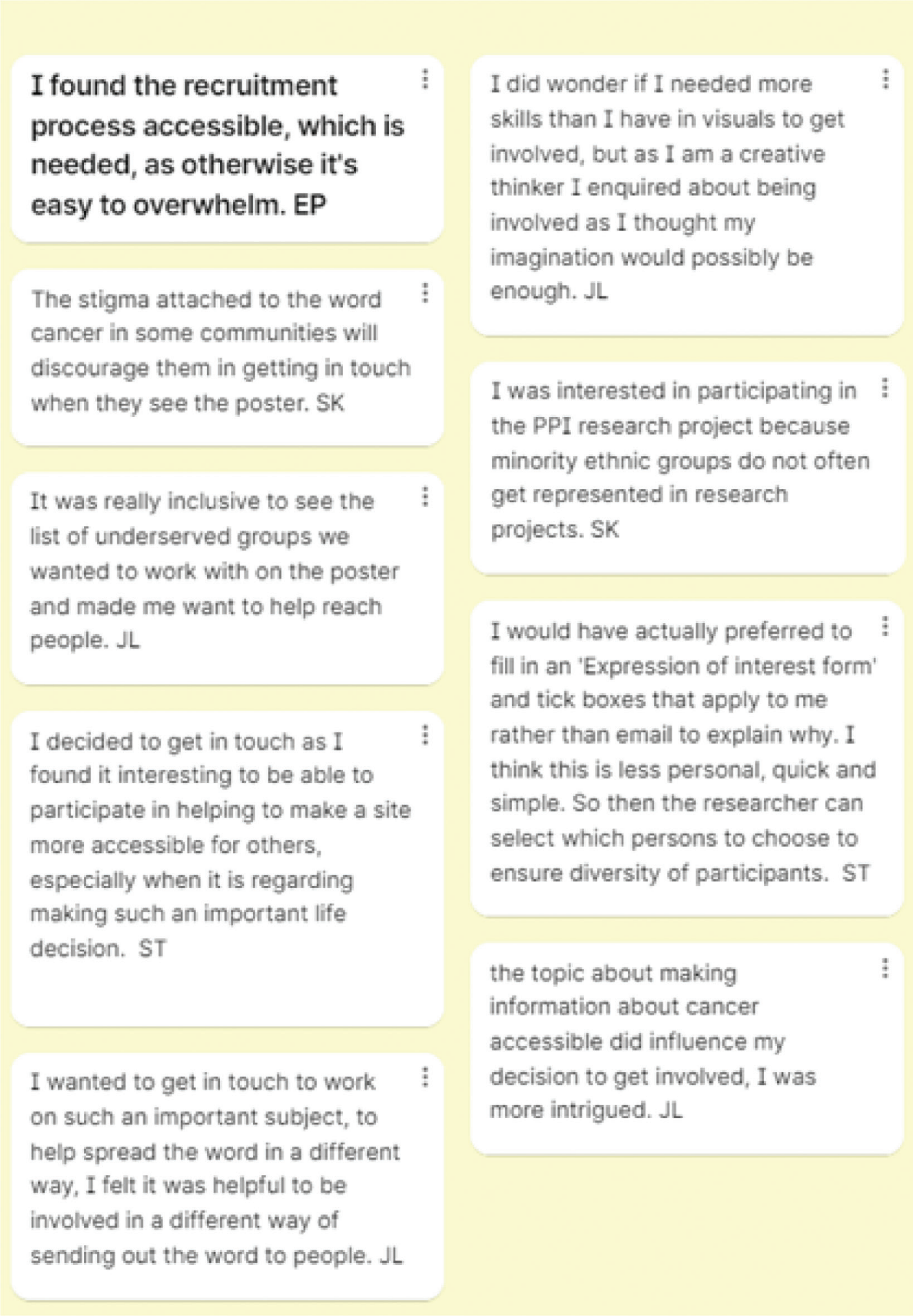
Can I bring a friend or family member?
Absolutely , please do! Please let us know if we can do anything to make it easier for you to take part.

Contact Details

Ethics ID: 78981. Take down date: June 2023

The team invited no more than five people to each workshop, to ensure that everyone would have a chance to contribute during the discussions. The workshops were scheduled for one hour, to make it convenient for people to fit them into their day and not too tiring. Evening and daytime options were provided. Contributors could also choose to have a one-to-one chat with a researcher instead of joining a workshop, if they preferred.

Figure 2. Excerpt from the recruitment to workshops reflections Padlet – bold text reflects the choice of the contributor, rather than additional emphasis (https://padlet.com/ksmorton/recruitment-to-workshops-h7q9regp2s9bjr8y)



I found the recruitment process accessible, which is needed, as otherwise it's easy to overwhelm. EP

The stigma attached to the word cancer in some communities will discourage them in getting in touch when they see the poster. SK

It was really inclusive to see the list of underserved groups we wanted to work with on the poster and made me want to help reach people. JL

I decided to get in touch as I found it interesting to be able to participate in helping to make a site more accessible for others, especially when it is regarding making such an important life decision. ST

I wanted to get in touch to work on such an important subject, to help spread the word in a different way, I felt it was helpful to be involved in a different way of sending out the word to people. JL

I did wonder if I needed more skills than I have in visuals to get involved, but as I am a creative thinker I enquired about being involved as I thought my imagination would possibly be enough. JL

I was interested in participating in the PPI research project because minority ethnic groups do not often get represented in research projects. SK

I would have actually preferred to fill in an 'Expression of interest form' and tick boxes that apply to me rather than email to explain why. I think this is less personal, quick and simple. So then the researcher can select which persons to choose to ensure diversity of participants. ST

the topic about making information about cancer accessible did influence my decision to get involved, I was more intrigued. JL

The contributors were asked to spend up to one hour on preparation, to enable people to see the decision aid beforehand, and to feel ready to contribute. They were encouraged to record their thoughts and ideas for images in any way that worked for them, including a written log, audio recordings or drawings.

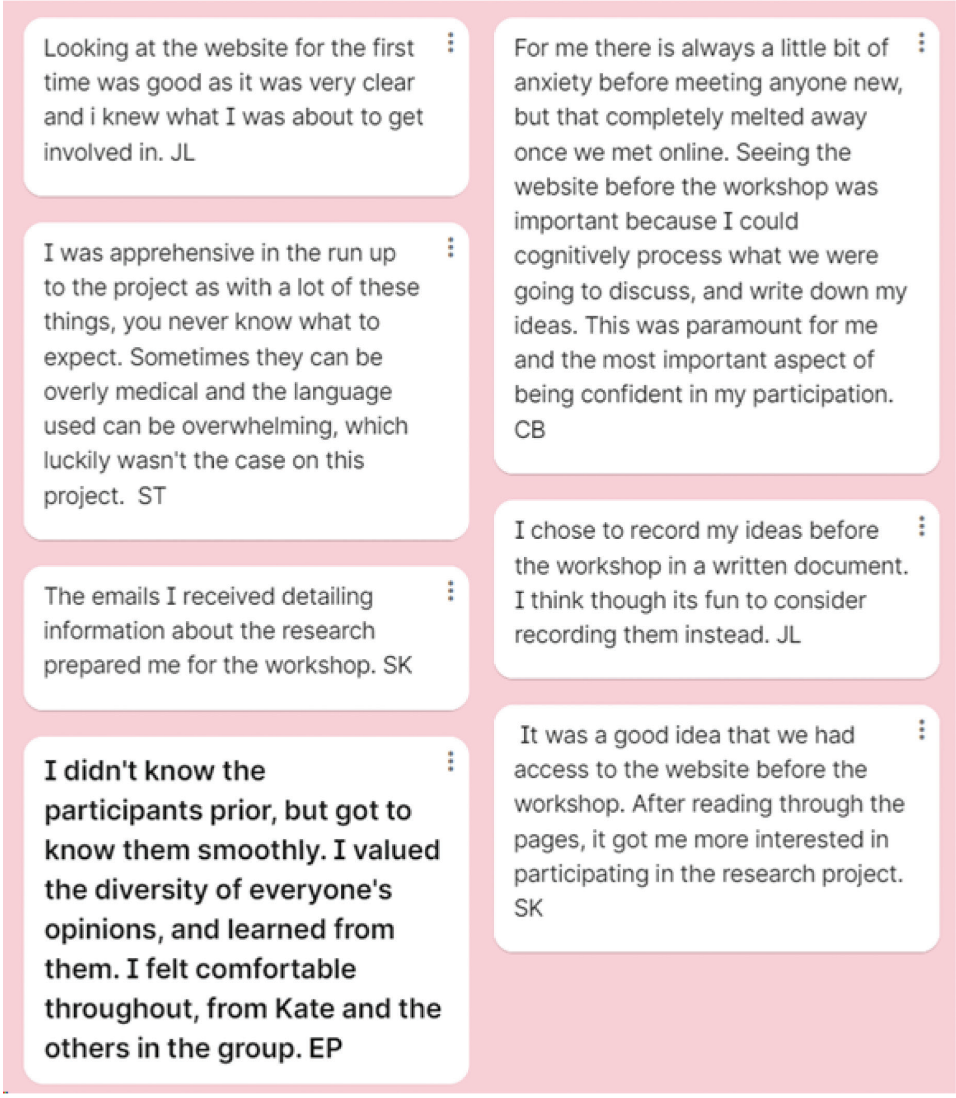
Reflections of public contributors about workshop set-up

Figure 3 shows an excerpt from the Padlet where public contributors shared their reflections about the workshop set-up.

Giving information in advance about what would be discussed was essential for public contributors to feel empowered, confident and ready to contribute. It is very important for public contributors to have clarity over their role and what they will be working on, as this helps reduce anxiety about what to expect. It was also reassuring for them to realise that they do have ideas and things to say about the topic. As one contributor wrote, 'When looking at the website for the first time, I was immediately interested and could think of ideas straight away, which I didn't think would be the case.'

However, there was still some anxiety before the workshop due to meeting a new group of people and not knowing who else would be there. As one contributor wrote, 'I felt a little nervous prior to the workshop because I wasn't sure the number of people attending.' Concerns that medical jargon might be used or that others would have more background knowledge on the topic could also cause nervousness.

Figure 3. Excerpt from the set-up of the workshop reflections Padlet – bold text reflects the choice of the contributor, rather than additional emphasis (https://en-gb.padlet.com/ksmorton/setup-of-workshops-prep-r4n7rt00omux43fm)



Looking at the website for the first time was good as it was very clear and i knew what I was about to get involved in. JL

I was apprehensive in the run up to the project as with a lot of these things, you never know what to expect. Sometimes they can be overly medical and the language used can be overwhelming, which luckily wasn't the case on this project. ST

The emails I received detailing information about the research prepared me for the workshop. SK

I didn't know the participants prior, but got to know them smoothly. I valued the diversity of everyone's opinions, and learned from them. I felt comfortable throughout, from Kate and the others in the group. EP

For me there is always a little bit of anxiety before meeting anyone new, but that completely melted away once we met online. Seeing the website before the workshop was important because I could cognitively process what we were going to discuss, and write down my ideas. This was paramount for me and the most important aspect of being confident in my participation. CB

I chose to record my ideas before the workshop in a written document. I think though its fun to consider recording them instead. JL

It was a good idea that we had access to the website before the workshop. After reading through the pages, it got me more interested in participating in the research project. SK

It is important that everyone knows beforehand that the workshop will not be technical, and that no specific knowledge is needed to take part. Ultimately no one should feel less empowered because they do not have the same level of education or knowledge of technical language.

Contributing to the workshop

Approach to workshop contribution

The artist (LB) and the researcher (KM) attended all workshops to discuss ideas with contributors.

In total, 18 contributors took part across four Zoom workshops and two one-to-one phone calls. Of the contributors, 14 returned for a second workshop/one-to-one call approximately four months later to view the images created by the artist based on their feedback, and to discuss further potential changes.

Table 1 shows a summary of demographic characteristics of the contributors, based on 13 people who filled in an optional demographic questionnaire. The researcher and artist who facilitated the

Table 1. Self-reported sociodemographic characteristics of the contributors who completed the optional survey (n = 13/18)

Sociodemographic characteristic		***n***
Age group	18–30	3
	31–40	3
	41–50	1
	51–60	4
	61–70	1
	71+	1
Gender	Woman	9
	Man	4
	Non-binary/genderqueer/agender/gender fluid	0
Sexual orientation	Gay/lesbian	2
	Heterosexual/straight	10
	Other – fluid	1
Ethnicity	Arabic	1
	Caribbean	1
	English, Welsh, Scottish, Northern Irish or British	4
	Indian	2
	Pakistani	1
	Any other Asian background	1
	Any other Black, Black British or Caribbean background	1
	Any other mixed or multiple ethnic background	1
	Any other White background	1
Low income or without a job	Yes	6
	No	6
	Prefer not to say	1
Access needs or living with a disability	Yes	7
	No	6
Genetic predisposition to cancer	Yes	2
	No	10
	Prefer not to say	1

workshops were White British, and did not have a genetic predisposition to cancer. Workshops were not recorded, but detailed notes were taken.

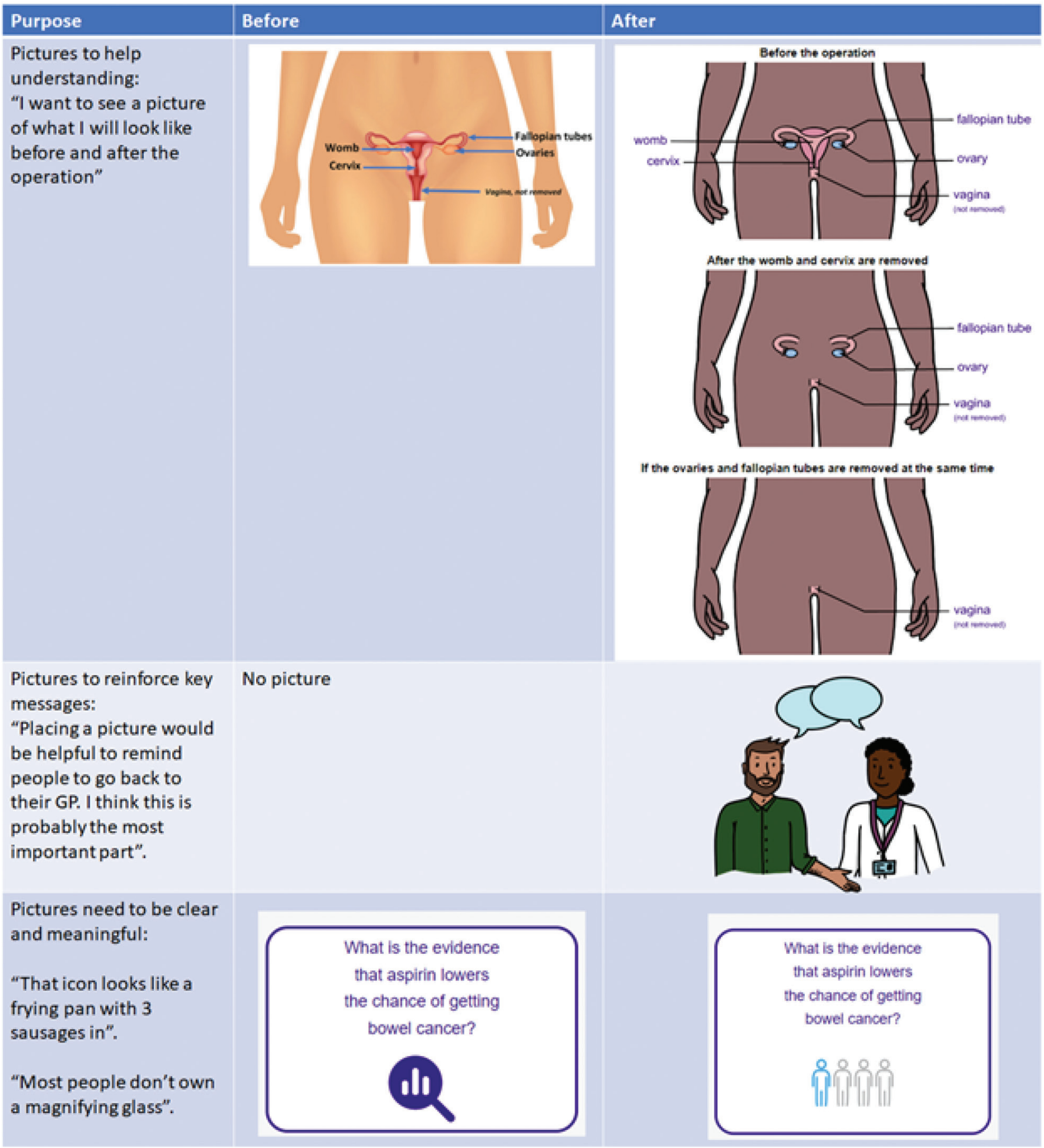
Figure 4 shows some examples of the accessible images co-created through the workshops.

Reflections of the contributors about the workshop contribution

Figure 5 shows an excerpt from the Padlet where public contributors shared their reflections about contributing to the workshop.

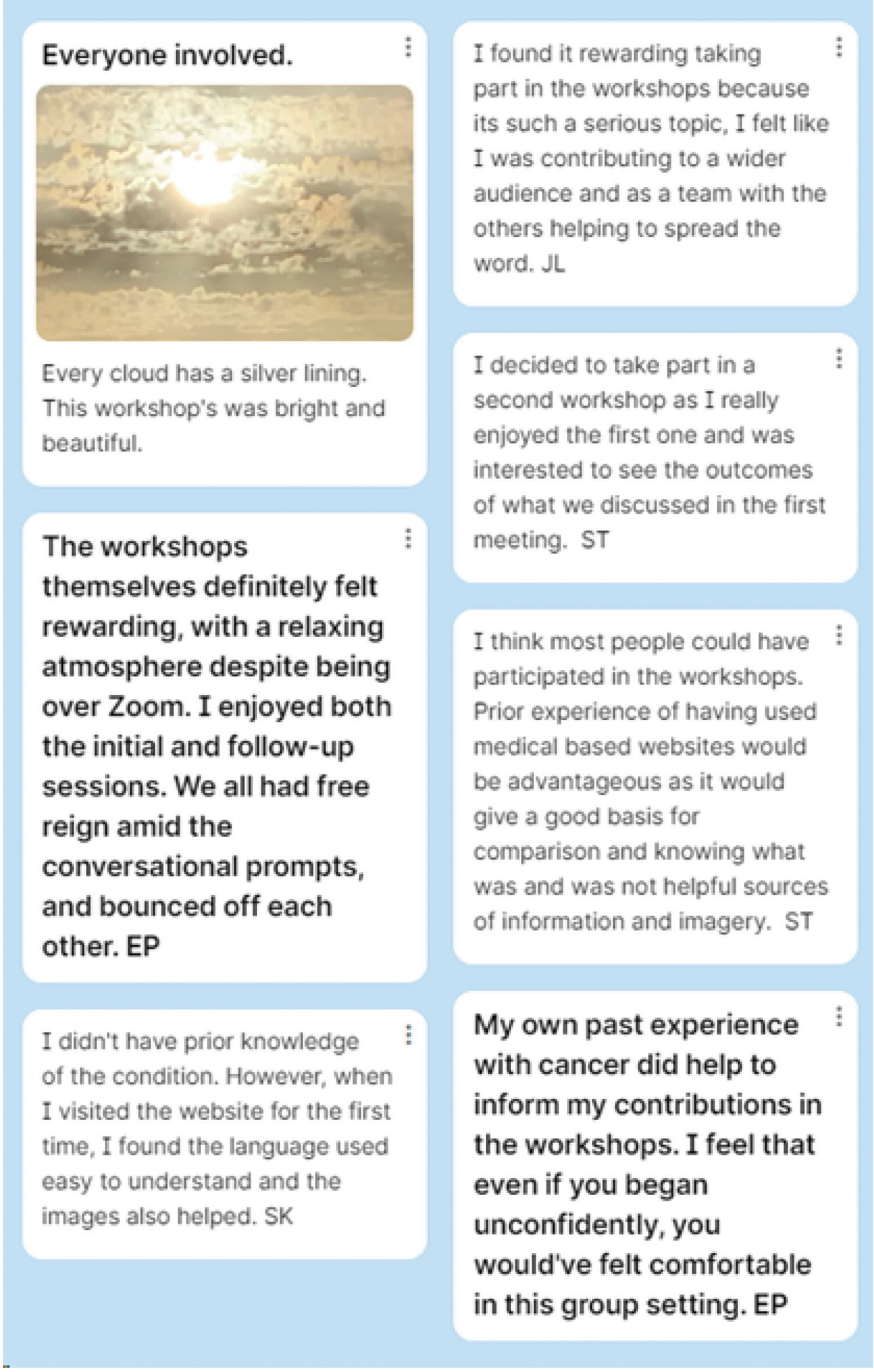
Things that stood out to make the workshops a positive experience included feeling respected and listened to, having the chance to talk, and feeling comfortable to talk. Being in a small group and being given space to talk helped to achieve this. Even serious, sensitive topics can be uplifting to discuss in a

Figure 4. Examples of the pictures created through the co-production workshops



Purpose	Before	After
Pictures to help understanding: "I want to see a picture of what I will look like before and after the operation"	Womb Cervix Fallopian tubes Ovaries Vagina, not removed	Before the operation womb cervix fallopian tube ovary vagina (not removed) After the womb and cervix are removed fallopian tube ovary vagina (not removed) If the ovaries and fallopian tubes are removed at the same time vagina (not removed)
Pictures to reinforce key messages: "Placing a picture would be helpful to remind people to go back to their GP. I think this is probably the most important part".	No picture	
Pictures need to be clear and meaningful: "That icon looks like a frying pan with 3 sausages in". "Most people don't own a magnifying glass".	What is the evidence that aspirin lowers the chance of getting bowel cancer?	What is the evidence that aspirin lowers the chance of getting bowel cancer?

Figure 5. Excerpt from the contributing to the workshop reflections Padlet – bold text reflects the choice of the contributor, rather than additional emphasis (https://en-gb.padlet.com/ksmorton/workshop-running-w0phq68lwbiko9tv)



Everyone involved.

Every cloud has a silver lining. This workshop's was bright and beautiful.

The workshops themselves definitely felt rewarding, with a relaxing atmosphere despite being over Zoom. I enjoyed both the initial and follow-up sessions. We all had free reign amid the conversational prompts, and bounced off each other. EP

I didn't have prior knowledge of the condition. However, when I visited the website for the first time, I found the language used easy to understand and the images also helped. SK

I found it rewarding taking part in the workshops because its such a serious topic, I felt like I was contributing to a wider audience and as a team with the others helping to spread the word. JL

I decided to take part in a second workshop as I really enjoyed the first one and was interested to see the outcomes of what we discussed in the first meeting. ST

I think most people could have participated in the workshops. Prior experience of having used medical based websites would be advantageous as it would give a good basis for comparison and knowing what was and was not helpful sources of information and imagery. ST

My own past experience with cancer did help to inform my contributions in the workshops. I feel that even if you began unconfidently, you would've felt comfortable in this group setting. EP

supportive environment, as shown by the image in Figure 5, illustrating that the workshop was 'bright and beautiful'.

Coming back to a second workshop was really valued, as public contributors could see their recommendations put into practice and their ideas come to life. As one contributor said, 'Seeing the changes meant that we had all been heard and our ideas given life.'

Some contributors felt that prior knowledge of the topic was not needed in order to contribute meaningfully, although one person said that 'my own past experience with cancer did help to inform my contributions in the workshops', and another said that 'I looked this [genetic predisposition to cancer] up before the workshop.' This suggests that even if co-production activities are designed to be open for anyone, a perceived lack of prior knowledge about a topic may make some people feel less confident about contributing.

Workshop evaluation and next steps

Approach to workshop evaluation

In total, 36 new images were co-produced for the decision aids (https://canchoose.org.uk/).
All contributors were invited to write about their experience for the University of Southampton Public Engagement website after the end of the workshops (https://www.southampton.ac.uk/per/support/funding.page).

Reflections of the contributors on evaluation and next steps

Figure 6 shows an excerpt from the Padlet where public contributors shared their reflections about the workshop evaluation and next steps.

It is important to consider the potential impact of co-production activities on people after the event. In this context, being exposed to information about the symptoms of cancer and genetic predisposition to cancer can have a big impact. As one contributor described, 'one thing I will never forget is that "bloating can be a warning and a sign of cancer"'. Considering how to support people if they have questions or concerns after taking part in co-production activities is important.

Knowing that a co-production activity leads to wider impact in the real world is an important incentive for people, for example, contributing to resources that will be used by patients may make them feel proud. It is also important to be aware that experiences of one co-production project can boost or damage confidence to contribute again, as having a positive experience of public involvement can encourage a contributor to do more on other projects.

Discussion

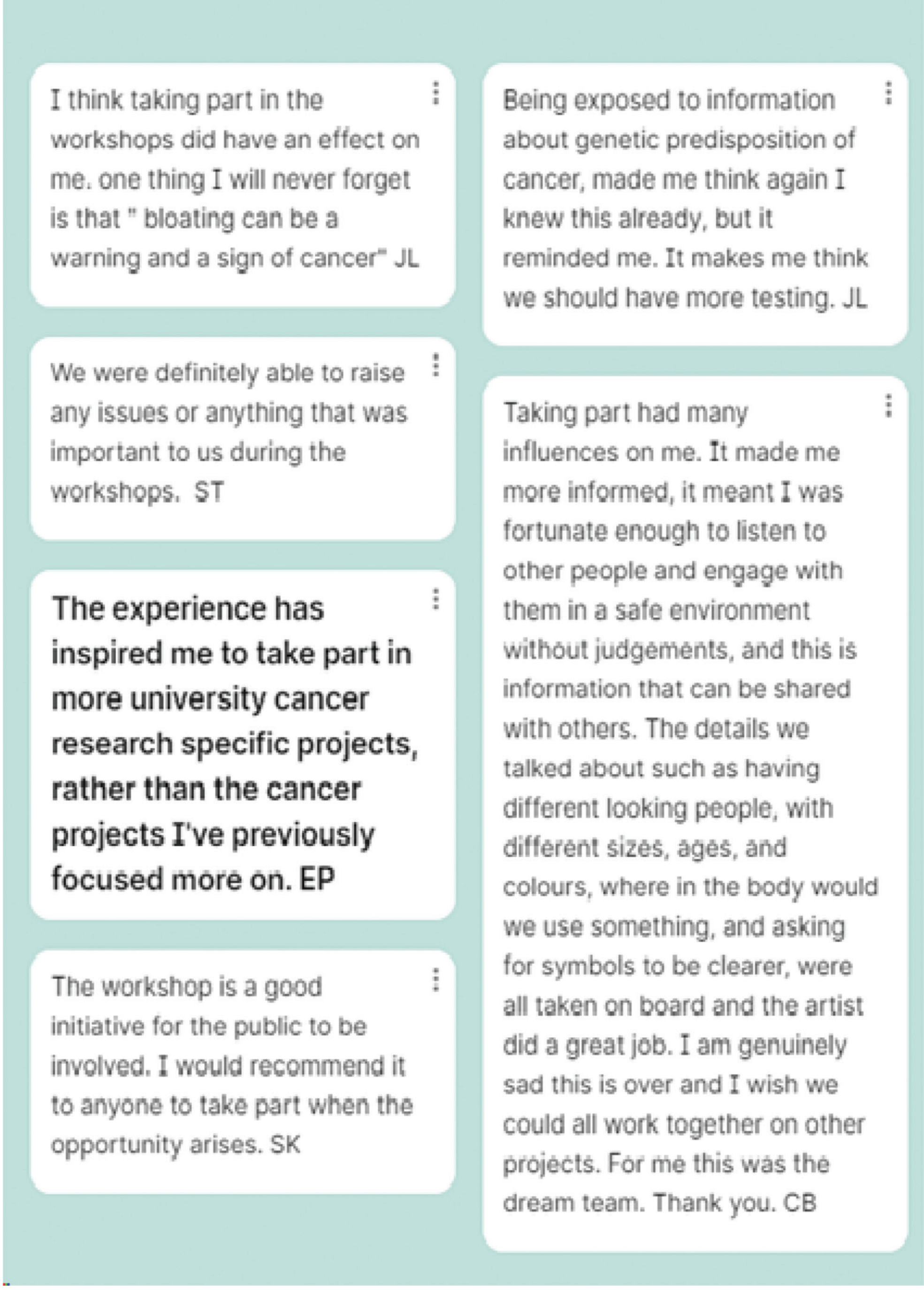
A co-production project can be quite small in scope and timescale, but it can still have significant impacts and implications for equitable working. This project was centred on a well-defined objective of co-producing images with marginalised groups to improve engagement and understanding of two decision aids, and the co-production methods worked well to ensure that decisions about which images were needed and how to design them were made jointly, and that power was shared.

The contributors' reflections shared here are important, as they support researchers to conduct manageable, meaningful co-production when creating decision aids, at a time when fewer than 10 per cent of patient decision aids involve patients as research partners during development (Vaisson et al., 2021). This article also demonstrates the strong motivation of people who have never been involved in research previously, and who do not necessarily have specific experiences relating to the topic in question, to support a project when they feel their voices matter.

We have co-produced some recommendations for research teams going forward.
Recruitment:

- Some people are unsure whether they will have the skills needed for a co-production project, and it is important that the team do everything they can to ensure that people feel confident to get involved, including making recruitment a warm, welcoming process, and working with existing contributors to think about how to increase other people's confidence to get in touch.

Figure 6. Excerpt from the workshop evaluation and next steps Padlet – bold text reflects the choice of the contributor, rather than additional emphasis (https://en-gb.padlet.com/ksmorton/evaluation-next-steps-l7jlb97i5y1vi828)



I think taking part in the workshops did have an effect on me. one thing I will never forget is that " bloating can be a warning and a sign of cancer" JL

We were definitely able to raise any issues or anything that was important to us during the workshops. ST

The experience has inspired me to take part in more university cancer research specific projects, rather than the cancer projects I've previously focused more on. EP

The workshop is a good initiative for the public to be involved. I would recommend it to anyone to take part when the opportunity arises. SK

Being exposed to information about genetic predisposition of cancer, made me think again I knew this already, but it reminded me. It makes me think we should have more testing. JL

Taking part had many influences on me. It made me more informed, it meant I was fortunate enough to listen to other people and engage with them in a safe environment without judgements, and this is information that can be shared with others. The details we talked about such as having different looking people, with different sizes, ages, and colours, where in the body would we use something, and asking for symbols to be clearer, were all taken on board and the artist did a great job. I am genuinely sad this is over and I wish we could all work together on other projects. For me this was the dream team. Thank you. CB

- Common concerns that might put people off getting involved in co-production include worrying that they will not understand medical jargon, feeling that they do not have enough knowledge or skills, and worrying about how much background knowledge other people might have on the topic. Explicit reassurance to address these concerns could be helpful, and working with public contributors to consider how best to do this can make sure that it is done supportively.

Set-up:

- Letting people know details such as how many other public contributors there will be, and that everyone is new to the project but has a shared interest in the topic, could go a long way to reassuring people before they take part. Ideally this information should be shared as early as possible.
- Inviting people to ask questions if there is anything else they want to know about the event is also important. Offering a quick one-to-one chat beforehand could be helpful if anyone is feeling apprehensive. This is important for equalising power, as everyone should know what to expect, not just the facilitator.
- One option for helping people to feel more comfortable beforehand is to ask each person to write a short sentence about themselves that can be shared with others in advance, although contributors may want to decide how to do this in a friendly, informal way that does not feel awkward.
- Sending information in advance about what will be discussed is hugely empowering and reassuring.

Workshops:

- When considering ways of working together or ground rules, always be considerate of individuals' preferences and avoid anything that could make people uncomfortable (such as having to turn on cameras during a video call).
- It helps to offer other ways to provide feedback, such as using the chat function during a group call or offering a one-to-one discussion, and to encourage potential contributors to let you know in advance of anything you can do to make them feel more comfortable.
- It is important to acknowledge the potential emotional impact of being involved. Openly discussing the option to step away at any time, or to turn off the camera if a contributor needs to, can help to normalise this. Having a support sheet ensures that everyone has this information without having to ask. Even just normalising that people might be upset by the information is important, as it may help people feel more able to discuss it, and this can often be overlooked (McVey et al., 2023).

Next steps:

- It is important that people can see how their input was listened to, and how it changed or shaped a project. The impact of co-production on a real-world issue, seeing changes to the project happen as a result of input, and the experience itself, can be very rewarding. Budgeting sufficiently to enable contributors to continue being involved in the next steps and dissemination of the work is important.
- It is also important to consider how to keep in touch with public contributors after the end of their involvement, if they would like ongoing updates about the project. People invest a lot of time and energy in public involvement, and they often become personally invested in the project, so they deserve to remain informed about what happens next. Plans should be put in place to ensure that all public contributors involved at any stage will be kept updated.

These recommendations build on existing guidance around effective working with public contributors (Witteman et al., 2018) and principles for co-production (Smith et al., 2023). Considerations about sharing power are a common thread in these guidelines, and the recommendations presented in this article include practical suggestions for equalising power from the outset, at recruitment. These recommendations are also particularly relevant in an era of increased remote methods of community engagement (Morton et al., 2023), and they apply well both to relatively short-term co-production projects and to long-term involvement over time.

The insights shared in this article were co-produced via an in-depth, meaningful and reflective process by a diverse group of public contributors. While we engaged in careful, open reflection to write the article, we are aware that there will still be groups whose views have not been heard. For example, we are aware that the majority of recruitment took place via online forums, thereby excluding those who do not have access to, or who do not use, the internet. The only in-person approach to recruitment was attending a local cancer information and awareness day run by a multifaith charity. Greater engagement with in-person events is time-consuming and requires sufficient resources, but it is important to enable a wider group of people's views to be heard. Going forward, funders need to support the time and resources required for meaningful, sustainable co-production activities with marginalised communities (Anderson et al., 2024).

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Declarations and conflicts of interest

Research ethics statement

The authors declare that research ethics approval for the project reported in this article was provided by the University of Southampton Ethics Committee.

Consent for publication statement

Not applicable to this article.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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